Editorials

AIDS—Science, Medicine, and Metaphor

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I WILL COMMENT on the AIDS [acquired immunodeficiency syndrome] epidemic from the vantage point of science, medicine, and metaphor. Along the way I will touch on the health care system, the "new virus," and a few other matters, but my overall goal is to persuade that AIDS is not "just another disease." Our response thus far has fallen terribly short. The discordance between biomedical scientific prowess and its application to the well-being of our people has reached an extreme point that requires rethinking. I will focus on AIDS because of who I am and what I do,* but for most of the problems and trouble spots of which I speak, the only thing new is the virus.

In just 11 years, a quarter of a million Americans have been diagnosed with AIDS; more Americans have died of this disease already than in the Korean and Vietnam wars combined; and the number of people now infected with the human immunodeficiency virus (HIV) is so great that we will soon exceed the death toll of World War II. Were there not another new instance of HIV infection beginning tomorrow, we would have our work cut out for us for the next decade just caring for those who are already on their way to illness.

If we do not realize that fully, it is because we have yet to embrace the fact that we must care. I am regularly astonished when politicians soberly discuss whether we can afford to care for people with AIDS—for the inference is that we have some choice. What alternatives do they have in mind? The issue is not whether but how, for the people with HIV infection are there, and they will need care.

Belinda Mason was a beloved colleague of ours on the National Commission on AIDS who died just a year ago at the age of 33. Before her illness became terminal, she had been a journalist and served as president of the National Association of People With AIDS. Throughout the two years I knew her, she expressed a profound wisdom I grew to value deeply. Once, when she was talking about the epidemic of fear and the resulting rejection and denial that so harass people trying to live with HIV infection, she commented that what we should really fear about AIDS is our society's failure to respond appropriately with care and compassion, for while we might in time learn to help people survive with HIV, in all of human history (she said), no society has ever survived that.

She went on to say,

> . . . people living with AIDS and HIV want nothing more or nothing less than what all of you take for granted . . . a place to live, the right to have a job, decent medical care, and to live our lives out without unreasonable barriers. We are not asking for extras, only to be included in what America already delivers to her privileged people.

We have learned much that we can or could do, including the most crucial of all—how to prevent HIV infection by avoiding risk. And yet, our Department of Health and Human Services predicts that there will be at least 45,000 but perhaps 80,000 new infections *per year* during this decade. That is appalling, but it gets worse, for in some parts of the world, population projections are having to be redrawn to take into account the negative effect of millions of projected AIDS deaths in upcoming decades. Of the populations that do survive, a dreadful number will be AIDS orphans. We should care about that. Despite attitudes to the contrary, Americans are not another species, and those demographic dynamics are pertinent to us. Indeed, these are dreadful, historic times! And yet, despite our resource-intensive health care system, we Americans are not using what we know. In fact, we are acting as if we do not have a problem.

With the most awesome epidemic of this century in full sway, the word one hears people say most often is "enough." "AIDS is just one disease, after all . . . haven't we done enough?" or "We've put enough into AIDS research—it is time to invest elsewhere." Or "Those AIDS activists have been entirely too effective for their cause—enough already!" I am always amused to hear people talk about the "powerful AIDS lobby" because—to a large extent—here she is. But the rest of that, to my ear, is another way of saying, "This has nothing to do with me or mine—it is those others," with the clear inference that those others are expendable. The first polio vaccine success came in 1955, after frightening years in which at most 50,000 cases of paralytic polio occurred in the worst summer. There were over 45,000 new cases of AIDS diagnosed last year! Can you imagine someone saying in 1952 that polio was just one disease and we had done enough?

Some of this comes from the layer of psychic insulation we seem to have developed around the fact that 37 million Americans lack basic health care. In Los Angeles County, a recent study revealed, 1.3 million people had been turned away when they sought health care in 1991. We should be shouting with outrage or convening urgent task forces to deal with such a shocking failure of our system. It is difficult to reconcile such startling default with the oft-stated American ideal of valuing each individual life. We are in the sole company of South Africa (among developed nations) in our failure to guarantee access to health care as a human right. Our patchwork "system" of health care is really no system at all but, rather, an entrepreneurial enterprise run amok. Almost no one is happy with it now, however advantaged; and the AIDS and drug epidemics have pressed so hard on its flawed fabric that ragged holes are gaping for all to see.

Here again, there is much we could be doing. A fringe benefit of epidemic effort over the past decade has been the innovation of cost-effective strategies to support people living with HIV or AIDS while reducing the number of hospital admissions. Outpatient care, home care, communal living arrangements in sheltered environments, and hospice alternatives all ease the costly drain on tertiary care hospitals; what is more, such alternatives can enhance and extend the quality of life. This alternative care is directly relevant to elderly and chronically ill patients and deserves amplification and support. But the deployment of such strategies has been left, to a large extent, to volunteers and community-based organizations that lack dependable resources to assure continuity. As a result, implementation has been spotty, and the remarkably dedicated people who have created these

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strategies frequently suffer burnout as a consequence of such lack of support.

And, of course, there is that other epidemic out there—so closely related to the spread of AIDS that we have coined phrases and talked about the twin epidemics of substance abuse and HIV, which in their most virulent form are Siamese twins. Whereas the sexual spread of HIV is relatively inefficient, injection drug use or crack cocaine-associated hypersexuality enhances the efficiency of transmission dramatically. Users know that and want "out," but here is a really shocking fact of American life—people who are addicted to injection drugs or crack cocaine but who want desperately to get out of the path of this awful virus cannot get treatment for their addiction if they are poor, despite a declared "war on drugs." And we are still arguing about needle access on the grounds that it "might seem to condone." Just look what we have condoned instead!

Tuberculosis is back with a vengeance. Why should that be a surprise? It was never gone, of course, just contained, like most of the other microbial pathogens we have tried to forget. Our policies have helped it rise like a phoenix from the ashes. And what a vicious creature that phoenix is, for now tuberculosis has a new, fertile substrate in people with HIV. In the complacency of recent decades, the budget slots were eliminated that should have provided the public health personnel needed to assure compliance with the long, tedious treatment necessary for eradication. Voila! Multidrug-resistant tuberculosis! We knew from our science that it had to happen, and we were correct. Where in the world do we think we are going, learning so many valid and important things and then ignoring what we know?

Science in the Era of AIDS

The Amsterdam conference in the summer of 1992 was a gathering of 10,000 hard-working persons dedicated to furthering the knowledge of effective AIDS care, HIV prevention, and fundamental science (no breakthroughs). It was also a striking sociologic phenomenon. Through diligence and special effort to include involved communities of all sorts, scientists and physicians found themselves in the company of activists and parascientific healers, sex workers and mimes, exotic ethnic dancers and dignified politicians—and from all corners of the earth. The result was kaleidoscopic, occasionally bewildering, and sometimes overwhelming.

AIDS, what an enemy! Transmitted by sex—one of the most biologically urgent and universal of human behaviors—and harbored for long, silent years by unsuspecting human accomplices whose expressions of love or lust carry occasionally lethal portent for the objects of their desire. It is not so hard, after all, to imagine how HIV survived—as it is thought to have done—for centuries in isolated human enclaves. With vertical transmission, long latency, and early sexuality, biologic survival could be maintained in families far too small to have sustained more flamboyant pathogens such as measles. A lethal virus that spreads through sexual transmission is a microbial assault weapon of awesome power—a worthy messenger of apocalyptic change.

We were at least partially prepared. I have often tried to imagine what would have happened had we not had a cushion of at least three decades of intensive investment in basic science to fall back on when AIDS surfaced in 1981. We are a generation of physicians and scientists who have been both blessed and cursed: blessed with scientific advance in the nick of time to enable us to understand the most dramatic, novel epidemic of our century, but cursed by the discontinuities and contradictions in our science and society that have threatened to render those insights ineffectual.

On the happy side, look what has been accomplished. We know a great deal about the pathogenesis of a complex retrovirus whose very existence was not suspected a decade ago. We are even clever enough to appreciate—if not yet to combat—the molecular sophistication of our adversary with its chameleon shifting of both antigenic and cytopathic properties.

We know lots more about the human immune system, too. The intricate circuitry of humoral and cellular immunity has been diagrammed, and the variety of immunologically active cells and of modulating interleukins has begun to rival the coagulation system in its rich complexity.

All of the advances have not just been analytic: we are learning how to care for people with HIV, to prevent infections and complications, and to extend a useful life of high quality for young adults whose years of potential life have been cut drastically short because they were unknowingly caught in the path of the silent, lurking virus of AIDS. Because of the pathogenetic intricacies of HIV, it has never seemed particularly rational to talk about a cure for AIDS, but it is clearly reasonable to try to extend years of productive life.

Vaccine work has been unpromising. Even partially effective vaccines for prevention are years away from general usefulness, and their evaluation and trials pose monumental problems—particularly because we already know what we need to know to avoid the virus a vaccine would be designed to prevent. Ethically we would be obligated to subvert the very substrate of efficacy trials by simple education for avoidance.

What is more, the developed world was served notice last summer in Amsterdam that populations appropriate for vaccine trial in Uganda would need to be assured access to current treatments and future vaccines on a quid pro quo basis, which is eminently reasonable but unprecedented. Even if we eventually master those logistic and ethical conundrums, a vaccine would only supplant—not replace—what we must do now, which is to confront and deal with the behaviors that put people at risk: thoughtless sex and injection drug use.

So while the news from the science front is fundamentally upbeat and exciting, there are sharp limitations to its usefulness. Given the enormous scale of the pandemic, we must be frank about what really needs doing—the first step to solving a problem is to see it clearly.

Before turning to medicine, I need to comment on some science we have not been doing. I am referring to social and behavioral science and the many facets of HIV and AIDS that are dependent on their advances. Nowhere is our lack of insight into behavioral determinants and interventions more striking than in the area of sexuality. We knew even before AIDS that we were undergoing a ferocious epidemic of other sexually transmitted diseases. And along with the escalation of infection with our new lethal pathogen have soared other kinds of trouble: the highest rate of teenaged pregnancy in the industrialized world, the highest rate of abortion anywhere that bespeaks a lack of information about and access to methods of pregnancy prevention, and other indicators of hope-

lessness such as drug use and violence that blight a whole generation of poor children in our troubled cities.

So there is much work to do, especially for our children. Yet, we have actually been blocked in efforts to do even the most carefully designed, peer-reviewed studies to describe current patterns of sexual behavior in the United States. Do you realize we are basing much of our strategic planning to deal with the most lethal sexually transmitted disease in history on the conclusions of Alfred Kinsey's study of the sexual behavior of a few thousand middle-class white men in Philadelphia? I hope they got it right back then, but who knows how it relates to today?

Let me go back to the Amsterdam conference, for a number of the themes I have been developing were illustrated by the most intensely covered "happening" there. My thoughts were jogged about our progress and problems when the press began its feeding frenzy over rumors of a "new virus." As it has turned out, there is no evidence of a new virus or even a new syndrome, but I would be willing to bet that anyone who is reminded of the Amsterdam meeting thinks about a "new virus" and wonders vaguely where that stands. Was it a new virus? What threat did it pose to public health? Finally—and this was an insistent question—In what way was this different from 1979? Were we on the brink of yet another outbreak of something new? These questions proved to be useful for achieving some perspective on these past incredibly turbulent years. The brief answer is that the few HIV-negative cases of immunodeficiency differed in virtually every way. These persons were said to be "just like AIDS patients" but lacked any evidence of HIV infection. Actually, they were not like AIDS patients. They lacked almost any unifying feature except for a low CD4 count. As the pursuit began, however, it sounded exciting. Even though there were few such patients, they were not clustered in time, and their suggestive clustering in place was more illusory than real because they had been referred to a few AIDS clinicians. We had learned so much about epidemic dynamics in all their complexity and were so sensitized to the potential importance of small clues that we were beginning to focus on dots on the television screen rather than on the big picture.

As it turned out, the "new virus" did not materialize. What seemed to reverse transcriptase activity in some tissue cultures belonged mostly to a mycoplasma—as a sadder-but-wiser virologist, let me assure you that that happens. What is more, the patients turned out not to have a "syndrome." In fact, other than low CD4 counts, they had little in common. And the blood supply issue, which had been raised instantly by the press—through clang association with events of the earlier era—was not an emergent cause for alarm. Whereas four of the patients had received blood transfusions at one point in their lives, successful follow-up of one of them found all three donors to have normal CD4 cells. Finally, analysis of HIV-negative intravenous drug users—reliable sentinels of blood-borne pathogens—showed normal CD4 cells as well. So there was no reason to raise alarms, and certainly not about the blood supply.

As the dust began to settle, the "feeding frenzy" element became clearer. In fact, the whole experience served as a reminder that there is too little distinction drawn between attention and alarm. It is thoroughly appropriate to be attentive and vigilant, for a day will come when another new pathogen surfaces. Before then, however, I hope we can learn to combine good judgment with our fancy technologies so that a sense of proportion prevails.

Medicine

Over the same decades in which virology, immunology, molecular biology, and pharmacology were racing along, medicine, too, underwent several kinds of remarkable transformations—some good and some not so good.

I will not go into detail about the technologic advances. Suffice it to say that the capacity to heal underwent several quantum leaps. Antibiotics, surgical procedures, and sophisticated diagnostic tools softened the shrouded image of hospitals as places where people went only to die. But much of our progress is coming more from pathogenetic understanding than from intervention, and a too-narrow appreciation of the source of our good fortune sets us up for trouble. Penicillin therapy does still work for syphilis, but prevention works better. We may be on the verge of a medical cure for ulcers, but alcohol still plays a role in 40% of internal medicine admissions. Birth defects from congenital rubella are nearly a thing of the past, but the effect of fetal alcohol syndrome is still being measured. Chemotherapy is offering intermittent cures and frequent surcease from dreaded cancers, but lung cancer is surging anyway, for the carcinogen still glows among us.

And then there is AIDS. It is common for people to ascribe the extension of useful life after a diagnosis of AIDS to the advent of AZT [acyclovir], but some argue that the prevention of *Pneumocystis carinii* pneumonia accounts for most of those added months and years. Other drugs have been moved into play for cytomegalovirus retinitis, for cryptococcal meningitis, even for *Mycobacterium avium-intracellulare,* but their development has seemed slow and their side effects threaten the quality of the months they help to buy. For those persons who have survived several years after diagnosis, the specter of lymphoma is now hanging over them. So therapeutic activism clearly has its limits even in fully developed AIDS.

The most sobering thing of all is the finding that—in what seems like a process of mass delusion or hysteria—large numbers of freshly graduated physicians admit to trying to pick their site of postdegree training based on where AIDS is not. That finding astonishes me, for there is no county in this land or country in this world where one can be sure of freedom from HIV. Real risks to health care professionals lie elsewhere. In 1987, of the 400 or so workplace-related deaths among 4 million health care workers in the United States, more than 200 were from hepatitis B and its complications, 19 were from electrocution, and none had anything to do with HIV. With universal precautions and hepatitis B vaccine, the health care workplace is safer than it has ever been—and the fear of HIV should give way to a committed implementation of universal precautions.

But beyond that misconceived issue of safety, why would one want to avoid participation in the epidemic of our time? I am afraid—getting back at last to metaphor—that it is because people have accepted the assertion that AIDS is God's punishment—God is punishing particularly bad people; those who get AIDS are the wrong sort, the throwaway people who are getting what they deserve. In grudging acknowledgment that there is something wrong with that sweeping condemnation, throughout these awful years one has heard

the phrase "innocent victim" with the clear imputation that the rest are guilty.

Yet, I know of no one who has gotten this virus on purpose. In contrast to people with a number of other diseases for which behavioral risks have long been recognized, the many dying now of AIDS were infected before it was even known that there was a virus "out there." The warnings we have tried to shout in more recent years have been rendered inaudible or incomprehensible through the static of mass denial—nowhere more typically than in a medical profession that still pretends it can hide.

That metaphor—of AIDS as God's punishment—brings me to the end of this soliloquy. Some years ago Susan Sontag pointed out how powerfully linked metaphor and illness could be.[1] A corollary is that evocative language can take on a pernicious and evil power if the wrong metaphor is chosen—we are liable to be captives of our own phrases and must be careful how we speak. After all, if we were truly to accept AIDS as God's punishment, should we not also deal with people with lung cancer as victims deserving of their fate? Should we not walk away from an accident victim who did not wear a seat belt? We will be learning much more about behavioral components to disease causation—and that trend would be ominous indeed if blame were to be partner to such understanding.

I contend that we have misunderstood the metaphor. If, indeed, we perceive AIDS as God's punishment, it is we who will be punished if we fail to rise to the challenge. We have raced forward with the intelligence to promote understanding and the talent to create technologies that not only allow us to intercede medically but that carry with them the obligation to care. After all, there is another metaphor at least as powerful that says we now live in a global village. Villages are busy, interconnected places where no one gets to remain a stranger. The whole world is pertinent to each of us now as never before. The AIDS epidemic reminds us—with its pandemic circling of the globe and its insistent reminder of universal sexuality, cultural denial, and adolescent risk taking—that we have more in common with our neighbors than we would once admit.

At the heart of both metaphors—the pernicious version of God's punishment of guilty persons and the positive one of a global village with all the interdependence that implies—is the issue of "others." In her lovely, eloquent speech to the 1992 Republican National Convention, Mary Fisher finally gave voice to Pastor Niemoeller's sad reflection from the days of the Holocaust:

> They came after the Jews and I was not a Jew, so I did not protest. They came after the trade unionists, and I was not a trade unionist, so I did not protest. Then they came after the Roman Catholics, and I was not a Roman Catholic, so I did not protest. Then they came after me, and there was no one left to protest.

From the same era, Charles Schoenbrunn brought forth a remembrance of his entry, as a reporter traveling with Patton's army, into one of the first concentration camps to be liberated. He tried to describe the horror of what he saw but abandoned the effort with a profound expression of inadequacy. Then he mused on how people could have been silent when such things were happening nearby. He discarded the possibility that they might not have known; the town was too close and the reek from the ovens too foul and pervasive. Finally he concluded that they must have found a way to put it out of mind because it was happening to others, and he commented that "it will only be when men and women learn to the very depths of their souls that there are no others that they will be saved from their own extinction."

We in the health professions are partway along a glorious road. The 20th century has yielded many biologic secrets of importance to the future of the human family, but only some of them come from the biomedical laboratory. Even those that do can be of use only if we recognize that we must learn to respect one another, to value prevention above intervention, however technologically dazzling, and, above all, to care. It is our privilege to be health professionals, and we must learn to know to the depths of our souls that there are no others.

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REFERENCE

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